Vol. 6 No. 2

April, 1994

# Seeking Opportunities: ASCC 5th Annual Conference

Mark your calendar for May 20th and plan to be at the Ferndale 4-H Center in West Little Rock for Arkansas Spinal Cord Commission's 5th annual conference, "Living With Spinal Cord Injuries in the 90's: Seeking Opportunties." This year's conference promises to be our biggest and best one yet.

**SPINAL CORD** 



Aric Fine, of the 1996 Atlanta
Paralympic Organizing Committee, will start off the morning with his insights into "Seeking and Finding Opportunities." Aric will discuss his personal experiences in seeking opportunities in education, relationships and employment as well as the opportunities he is working to provide athletes and spectators alike at the Atlanta Paralympics.

Another feature of this year's conference will be a presentation by Dr. Stevenson Flanigan, Professor of Neurosurgery at the University of Arkansas for Medical Sciences. Dr. Flanigan is former Medical Director of the Arkansas Spinal Cord Commission and physician

to many people with spinal cord injuries in Arkansas. He will be discussing his views on the evolution of spinal cord injury care in Arkansas. Hopefully, all of his former patients and staff will be present to hear his talk.

In addition, concurrent sessions will cover topics including infertility and spinal cord injury, a research update, assistive technology and computers, recreation, urology and spinal cord injury and family issues. An afternoon session on wheelchair seating and positioning is designed particularly for rehabilitation professionals.

Of course, no conference would be complete without exhibits and they will be there, as well as a resource center, opportunities to meet old friends and make new ones and a day full of learning and fun. Registration brochures have already been mailed, so be sure to register early (scholarships are available to ASCC clients and their care providers). If you have questions about the conference or registration, please contact Dee Ledbetter at 324-9620.

The Arkansas Spinal Cord Commission thanks our co-sponsors of this year's conference - we couldn't do it without you!

Baptist Rehabilitation Institute
Continental Medical Systems
Central AR Rehabilitation Hospital
Northeast AR Rehabilitation
Hospital
Northwest AR Rehabilitation
Hospital
HealthSouth Rehabilitation
Hospital of Ft. Smith
St. Michael's Rehabilitation
Hospital
Baylor Institute for Rehabilitation
Shepherd Spinal Center

## **ASCIA Announces 1994 Scholarships**

The Arkansas Spinal Cord Injury Association (ASCIA) is now accepting applications for their second annual scholarship program. Five \$500 scholarships will be awarded. To apply, the individual must have a spinal cord disability, be accepted for enrollment at an educational or training institution for the Fall 1994 semester and submit a scholarship application to the ASCIA Scholarship Committee by May 10, 1994.

Contact ASCIA President Adrian Horton at 568-6406 or Scholarship Chair Cheryl Vines at 324-9624 or 834-8513 to obtain an application.

All applications will be considered by a review committee and scholarships will be awarded at the ASCC Conference on May 20th at the Ferndale 4-H Center. Previous recipients may apply again this year, since scholarships may be awarded twice to the same recipient.

If you're heading for school this Fall, you should apply for an ASCIA scholarship.

#### SPINAL COURIER

Published quarterly by Arkansas Spinal Cord Commission

Cheryl L. Vines Executive Director

Thomas L. Farley Editor

The Arkansas Spinal Cord Commission does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services.

# **BUCKLE UP!**

## POTTY WARS!!!

Dear Editor:

Last summer in "Dear Abby" and in this week's "Ann Landers" columns there were letters from people questioning whether it is appropriate for people who don't have disabilities to use handicapped restroom stalls. Both writers said that they had done it, when no one else appeared to need it and had been criticized. I must admit, I frequently use the handicapped stall because I'm interested in checking out the accessibility. Abby's answer was "never use it," but Ann said "only in emergencies." I'm concerned because with the ADA, some establishments have modified their restroom leaving just one accessible stall.

I'm interested to know what people who use wheelchairs think! Is it "reserved only for people with disabilities" or "first come/first served"? I'd love to hear from our readers on what they think.

Cheryl Vines
ASCC Executive Director

## SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

# FEMALE CATHETER USERS

Dear Editor:

A tip for all newly injured females - you can catheterize yourself from your chair without too many problems if you use a disposable leg bag. Just connect your catheter to the tubing that is connected to the leg, empty into it and drain the leg bag into the commode. Be sure to rinse the bag with cold water.

This is very easy and useful, especially if you are out and the bathroom is not quite large enough. You don't have to be right up at the commode, just close enough to empty the leg bag. Also, it is best if you get the large bag and one with a Flip-Flow valve (not just a cap on the end).

Female Client, age 37

# HOME REPAIR LOANS AVAILABLE TO LITTLE ROCK RESIDENTS

Dear Editor:

Block Grant program of Little Rock has announced the availability of loans for low income elderly or handicapped homeowners to help with repair to their homes. The limited home repair loan doesn't have to be repaid if the borrower keeps title to the property and occupies it as his principal residence for at least five years.

These loans are available to homeowners living in the city limits of Little Rock who are 62 years of age or older, or are permanently disabled. Applicants must also meet income eligibility guidelines. For more information call 371-6825.

Martha Henderson ASCC Case Manager

## MISSING VIDEOTAPE FROM ASCC RESOURCE LIBRARY

Dear Editor:

I have two items. First, please let the Courier's readers know that one of our original tapes from the June 1993 Conference is missing. It covered the "Can the Injured Spinal Cord Be Rebuilt?" session presented by Dr. John Houlé, and is tape number 103. If anyone has this videotape, please return it to the Resource Library as soon as possible or call Karen Schmidt at 324-9628.

Also just a reminder, the ASCC Resource Library has a check-out time of two weeks for books and videotapes. Please return items borrowed from the Library in a timely manner so others may check them out also. Thanks for your help and cooperation!

#### MOBILITY ASSISTANCE

Second, I have a list of several automobile manufacturers that offer "mobility assistance" on the purchase of a new vehicle. This assistance ranges anywhere from a \$500 rebate to a wheelchair lift. Call me at 324-9628 to get the toll-free phone numbers of these manufacturers.

Karen Schmidt ASCC Information and Resource Coordinator

# **HIGH PROFILE!**

# DAN STELL

This is the third in a series of articles profiling ASCC Case Managers.

Dan Stell began his career as a Rehabilitation Counselor in 1969. After 24 years of service in this field it appears he has found his niche in life.

Dan's relaxed, steady manner enhances his ability to put people at ease. This attribute has enabled him to develop the confidence and trust necessary for a positive working relationship with the clients he serves as well as other professionals. In addition to instilling confidence in others, Dan is also considered "the stable force" in the Little Rock Case Managers office. Oftentimes through the years he has effectively maintained the entire Little Rock caseload due to numerous case manager vacancies and absences. His years of expertise have definitely been most advantageous during these times.

Along with Dan's undergraduate degree in sociology/psychology, his Masters in Rehabilitation Counseling from University of Central Arkansas has provided the necessary educational background to assist him in developing resources and services for individuals with spinal cord injury. One of Dan's greatest assets is his knowledge and skill in providing technical assistance and maintaining service coordination with other agencies. A very successful endeavor has been the implementation of a peer support group in Conway with the assistance of

Veterans Administration Spinal Cord Injury Coordinator, Ben Hollis

According to one of the peer support group members, "As a Case Manager, Dan is always there to help with your problems and he doesn't quit until a solution is



found." Statements such as this are heard quite often and only confirm his persistence and dedication as an ASSC Case Manager.

**FAMILY MEMBERS:** Wife Annie, daughter Dawn, age 16.

PHRASE TO SUM ME UP: Being fair with people. There has to be trust and confidence in developing a positive relationship.

FAVORITE WAY TO UNWIND: I love to play tennis. That is my 'fun' time. My goal for some time has been to win the City Tennis Tournament in Conway where I live. I was runner-up one year. I was also runner-up one year in Morrilton. Not winning was one of my biggest disappointments in a long time.

### **BEST ADVICE TO A NEW CASE MANAGER:**

The client benefits more by your teaching him how to solve a problem than he would if you solved it for him. I think it is best said by the proverb, "Give a man a fish and you provide his meal. Teach the man to fish and you feed him for a lifetime."

MOST SIGNIFICANT ASPECT OF MY JOB: It allows me the freedom to be innovative in serving clients.

LAST BOOK I'VE READ: It Doesn't Take a Hero which is an autobiography of General H. Norman Schwarzkopf. I admire him because of his focus, integrity, and ability. He was the right man at the right time in the right place during the Iraqi war.

#### WHY DID I DECIDE ON REHABILITATION

COUNSELING: It's a tool that can be used to enable a client to improve his or her quality of life. In comparison to my other work experience this seems the most significant.

## WHAT IS A CASE MANAGER?

Someone may have introduced him or herself to you as a Case Manager from the Arkansas Spinal Cord Commission (ASCC). If this happened while you were in the hospital or rehabilitation, you may have been so swamped with new faces and information that you hardly remember anything.

# So What Is A Case Manager and What Does One Do?

When a Case Manager meets you, you are his/her main concern at that time. He/she cares that your life has been changed (usually in a split second if you were injured). A lot of questions will be asked that you have probably heard before, but are necessary in order to help you. You've been through a lot and your Case Manager may be the one who can help you through the ordeal. If this is not comfortable, a referral on your behalf can be made to a qualified

counselor or a peer counselor - someone who has had an injury like yours and knows first hand what you are experiencing.

### How Is Your Case Manager Going to Help You?

He/she will visit with you during your hospitalization, talk to members of the medical team and your family to determine the best plan to meet your needs upon discharge. If you are a veteran or have an insurance representative, some of these things may have already been decided. Your Case Manager makes sure the job gets done. The "job" includes making your house accessible if you go home in a wheelchair and making sure you have all of the necessary equipment.

Assistance with locating appropriate resources (e.g., social security

disability, SSI, low cost housing, etc.) will be provided to you and your family. You will receive guidance in setting realistic goals and making informed decisions. Your Case Manager wants what is best for you, but does not make any decisions for you. He/she will provide you with facts and informational resources; then it's up to you and your family to make decisions regarding your care, living arrangements, etc.

Your Case Manager is knowledgeable in all aspects of spinal cord disabilities and is trained to recognize potentially serious medical problems. He/she will ask questions about your medical care during visits and phone calls. Referrals on your behalf can be made to a spinal cord injury clinic or, if necessary, a specialist.

You and your family will be working with a variety of

people, but your Case
Manager is the person to contact if you have problems or don't know who to contact for assistance.

If he/she doesn't have the answers you need, assistance will be provided to help you find them.

# Will My Case Manager Pay Some of My Bills?

Maybe - it depends on many things. If you are medically eligible for our registry, then you are eligible for case management services. Depending upon your income, you may be eligible for some "purchased services." Such services often include the purchase of durable medical equipment (e.g., wheelchairs, shower chairs, braces, etc.) and help with some home modifications. Funding for these items is subject to availability. We operate on a budget just like you do.

However, ASCC cannot assist with paying for something that has already been purchased. If it is not authorized **before** it is purchased, we can not pay for it. Also, certain items, such as rent, utilities, food or hospital bills cannot be paid by ASCC.

# How Can I Best Work With My Case Manager?

You and your Case Manager will need to work together on achieving independence. An honest, open relationship will enable you to receive assistance in finding all available resources to meet your needs. You will need to take personal responsibility, such as learning how to properly care for and maintain your wheelchair and other equipment.

Call your Case Manager when you move or change phone numbers. Also, call if you go into the hospital. You, your health and well-being are important to us. As your needs change, additional assistance can be provided.

# How Long Will I Have a Case Manager?

As long as you are a resident of the state of Arkansas and meet the medical eligibility criteria, you will have ASCC services.

You and your Case Manager will determine how much or how little contact you need. Clients who are working may be satisfied with only once a year contact with their Case Managers. Others are contacted every three or six months. A few prefer not to be contacted at all and, at their request, may be put in a status that keeps them on the caseload and allows them to receive the quarterly newsletter without a call or visit. If there are specific needs, especially with new injuries, calls or visits may be needed more frequently.

If you have any questions regarding the Case Management Program, call your Case Manager or Patti Rogers, ASCC Client Services Administrator, at 324-9624.



## NEW VISTA VOLUNTEER

Karen Schmidt began work full time at the Commission on February 14, 1994, as the new VISTA Volunteer for the Education and Resource Center. She is available to assist anyone who wants to find information in the Resource Center and will be gathering resources from other areas that would be of interest to people with spinal cord disabilities.

Karen is a single parent who was involved in an auto crash five years ago and has paraplegia at the T12-L1 level. Originally from Texas, Karen has lived in Arkansas for the past 11 years. Before coming to work at ASCC Karen was a Registered Medical Assistant for Dr. Carole Jackson of Conway. Karen, her eight-year-old son Chris and their Boston Terrier, Earle, now live in Vilonia.

Describing her new position, Karen said, "Anyone who has not seen the Resource Center needs to stop by and visit. If you live too far away to visit and would like some information, then you can always call me at 324-9628 and I'll be happy to mail it to you."

"Watch the newsletter and I will keep you updated on the newest videos and resource books we have," Karen continued. "I am really looking forward to my job, and together with your help,we can make the resource library a huge success!"

## SPRING FLING AT MAUMELLE PARK

Join your friends at Maumelle Park on Saturday, May 14 for a day of eating, entertainment and fun. Case Managers in the Little Rock office are inviting all clients and care provider or immediate family member to Pavilion #4 at Maumelle Park at 10:30 a.m. There will be activities for children and adults and lunch will be provided (but you MUST call and let us know how many you will bring so we will have enough food). Come prepared to have a good time!

Directions: take Highway 10 (Cantrell Road) West 2.6 miles past Interstate 430, turn right on Pinnacle Valley Road, go 1.5 miles to a large yellow house, turn left and proceed to the entrance of the park. The gate attendant will direct you to Pavilion #4. Call 324-9628 to make your reservation.

## Juniors are Rollin . . .

The Jr. Rollin' Razorbacks are off to a great start, winning one game in their first tournament in Tulsa, Oklahoma on February 12-13. The team beat Kansas City in a close one, 26-24, but weren't as succeessful in their other three games. Basketball season is over for this year, and many of the Juniors are turning their eyes to track and field competition. Since track is not a team sport, Junior athletes can practice on their own for regional competitions. If you are interested in getting involved in Junior track and field competition, call Coach Doug Garner at 525-4503 or 767-9185.

# **Camp Aldersgate Dates Set**

Mention Camp Aldersgate to any child who has been there and you'll get an earful: swimming, parties, cookouts, boating, horseback riding and more. Camp not only provides a wide range of scheduled activities but it provides a growing experience for the child and parent as well.

The dates for camp this year are June 12-17 for ages 6 through 11, and July 3-8 for ages 12 through 16. Camp is open to young ASCC clients with spina bifida and other spinal cord disabilities. All camp buildings are wheelchair accessible and air conditioned. Twenty -four hour medical coverage is provided and all campers receive one-to-one supervision by trained counselors and volunteers.

Application forms have already been mailed to prospective campers and need to be returned by May 16, 1994. If your child did not receive an application, please call Betty Massey, ASSC Camp Coordinator at 501-324-9624.

The Arkansas Spinal Cord Commission is sponsoring these two weeklong sessions in cooperation with MedCamps of Arkansas, Camp Aldersgate and Spina Bifida Association of Arkansas with the help of many community contributions..

#### OOPS!!!!!

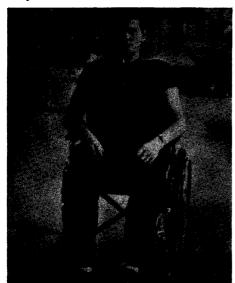
The last issue of the Spinal Courier included a list of support groups being held around the state for people with spinal cord injuries. Unfortunately, we unintentionally omitted one of the oldest, most established groups around! Please add the SCI Support Group and SCI Caregivers Support Group to your list. They meet the third Tuesday of each month at 6:30 p.m., HealthSouth Rehabilitation Hospital of Fort Smith (formerly Ft. Smith Rehabilitation Hospital), 1401 South "J" Street, Ft. Smith, Arkansas. Contact Connie Weiderspann at 785-3300 for additional information.

## A SIMPLE COSMETIC PROSTHESIS

by Shirley McCluer, M.D.

Many non-ambulatory lower extremity amputees would like to have a prosthesis for cosmetic purposes, but when they request one they are told that the cost of a conventional prosthesis cannot be justified for appearance only. However, there is an excellent solution that costs little or nothing!

The individual in this photograph is a paraplegic with bilateral hip disarticulation amputations. The cosmetic legs he is wearing were constructed out of ordinary household items and they look and feel very natural.



Materials Needed:

- One pair of stockings or panty hose - any type will do, but the old-fashioned thick cotton stockings are preferable if they can be located.
- · One metal coat hanger.
- One package of synthetic quilt batting ( or any type of stuffing material, including rags).

#### Construction:

Open the coat hanger so that it is a single strand of wire. Stuff the stocking as full as desired, with an attempt to duplicate the approximate size of the remaining leg. Insert the coat hanger wire down the center of the stuffed stocking. The purpose of the coat hanger is to give some stability and rigidity to

the leg. Measure the location of the knee bend from the foot (based on the other leg) and bend the coat hanger to keep the "knee joint" flexed to 90 degrees. If necessary, a similar bend can be made for the ankle to help hold the shoe in place, but this would need to be done first.

Put on a pair of shoes, socks and trousers and pin the stocking to the inside of the trousers to hold the leg in place. I defy anyone to recognize that the leg is not real!

#### Advantages:

- Low cost.
- A soft, natural feel if anyone accidentally bumps or touches it.
- Minimal weight to interfere with transfers.
- No hard surface to cause pressure sores in anesthetic areas.

For spinal cord injuries this type of leg is actually better than a commercial prosthesis.

In my experience, it is better to show a potential candidate the above picture so they can see how real the leg looks <u>before</u> telling them what it is made of.

## NEW GYN CLINIC!

Since 80% of spinal cord injuries are male, most of the medical items reported in this column relate primarily to men. However, this time I have news specifically for women. I have been concerned for many years about the difficulty women with disabilities have in receiving basic gynecological care. Many doctors' offices are not wheelchair accessible and the nursing assistants in the office are not familiar with good, safe techniques for transferring a patient to an examining table.



For several years I tried to start a specialized gynecology (GYN) clinic at Baptist Rehabilitation Institute, but was never able to find a gynecologist who was willing to take on the project. However, the search has now been successful!

Beginning in May 1994, Baptist Rehabilitation Institute in Little Rock will have a monthly GYN clinic specifically for women with disabilities, regardless of the type of disability. Patients may refer themselves to the clinic or they may be referred by another physician. The clinic will be shared by two excellent Gynecologists, Dr. Janet Cathey and Dr. Karen Kozlowski.



The kind of problems that might be appropriate for this clinic are: routine pelvic exam and PAP smear, menstrual problems, contraceptive counseling, prepregnancy counseling (that is, discussion about the advisability of pregnancy in relation to the disability), sexual counseling, etc.

The first clinic will be held on Friday, May 20, 1994. To make a referral, call Betty Phillips at 223-7028.

# Pamphlet Helps Authors in Writing about People with Disabilities

Most of us, as children, can remember using the saying, "Sticks and stones will break my bones, but words will never hurt me." Although we usually used it to defend ourselves from the verbal harassment of others, we knew even as we said it that it wasn't true and it still isn't true today. Words do hurt and they have more opportunity to hurt when put in print for the world to see.

Today writers and other professionals who communicate with the public unintentionally portray people with disabilities in an insensitive manner through use of inappropriate terminology or through poor choice of words. To address this problem The Research & Training Center on Independent Living at the University of Kansas has developed a pamphlet entitled Guidelines for Reporting and Writing about People with Disabilities.

The Guidelines explain preferred terminology and offer suggestions for appropriate ways to describe people with disabilities. Developed from input from over 100 national disability organizations, the Guidelines have been endorsed by media and disability experts. Portions of the Guidelines have been adopted into the Associated Press Stylebook, a basic reference for professional journalists.

If you don't know the difference between a disability and a handicap or don't know when it is proper to use the term "birth defect" (never) then you need this pamphlet.

Copies of the Guidelines are available at no charge from the ASCC Educational and Resource Center or contact The Research & Training Center on Independent Living, 4089 Dole Building, University of Kansas, Lawrence KS 66045. You can also phone: 913-864-4095 (voice/TDD) or fax (864-5063).

# What do you know about the **Americans with Disabilities Act**?

Probably not enough!

If you are a

Person with a disability
Parent of a child with a disability
Business owner
Or just a concerned citizen

Then, the ADA Roundtable has a service for you.

Expert speakers trained in the ADA will come to your group or organization to provide information on the inclusion of people with disabilities into the areas of:

Employment
State and Local Government Programs
Public Accommodation
Telecommunications

Programs can conform to your special interests.

To take advantage of this statewide service, contact ADA Roundtable Training Coordinator Jean Ellen White in Hot Springs at 624-7710, or 1-800-382-1148 Voice/TDD.

## PEER SUPPORT NETWORK ON THE MOVE

Thirteen individuals with spinal cord disabilities have completed the required training for participation in the Peer Consultant Network as Peer Consultants. The five hours training covered information such as communication, establishing relationships, confidentiality, sexuality and role playing scenarios.

Congratulation to our thirteen newly trained Peer Consultants:

Randy Alexander, Hot Springs
Craig Blanchard, Hot Springs
William Britt, Little Rock
Adrian Horton, Little Rock
William Huskey, Salem
Eloise Kemp, Little Rock
Carolyn Kerr, Little Rock
Jim Lewis, Little Rock
Torin Lewis, Little Rock
Mike Long, Little Rock
Mark Morlen, Hot Springs
Karen Schmidt, Little Rock
Roger Sheeley, Walden

These Peer Consultants have volunteered to provide information, understanding and support for individuals with new spinal cord injuries and their families. Everyone who experiences a spinal cord disability must cope with a major and painful loss. The physical and emotional impact of this experience is significant, not only for the people who are injured, but for their family and friends as well.

Sometimes talking with another person who has gone through a similar experience can help the newly injured individual on the road to a healthy adjustment. If you know of someone who could benefit from this program or if you would like to become involved with the Peer Support Network contact Horace Love, Peer Support Coordinator, at 324-9620.

Thanks again, Peer Consultants, for making this Network possible!

# From the Director

"Not being able to walk wouldn't be so bad, it's all the other things that spinal cord injuries do to you that make it such a hassle to live with...." It's been nearly 20 years since a man I met as a student working in a rehabilitation center told me that. As amazing as it was to me at first, it has stuck in my mind for all these years. And, I have learned, he was not alone in his assessment; I've heard the same theme repeated by many people with spinal cord injuries over the years.

Bladder, bowel, sexual functions, pressure sores, chronic pain and even day-to-day hassles with accessibility issues and attitudes have a significant impact on the lives of people living with spinal cord injuries. We even have terms for them now - "secondary conditions." By definition, secondary conditions are those resulting from the incidence if a permanent disability. Yes, that can include a lot of different things. The Spinal Cord Commission was established, at least in part, to assist people in dealing with secondary conditions - we just didn't use that term back then.

I think you'll be hearing more about secondary conditions. There is now a federally funded Research & Training Center on Secondary Conditions in Spinal Cord Injury at Spain Rehabilitation Center in Alabama. Prevention of secondary conditions has also become a primary interest of the Disability Prevention Program at Centers for Disease Control and Prevention. Even researchers are beginning to look at their basic science research in terms of restoring other functions, along with walking.

The Spinal Cord Commission is undertaking a project to define which secondary conditions affect Arkansans with spinal cord injuries and what can be done to prevent them. We are just finishing a project that looked at secondary conditions in people with spina bifida in Arkansas. Look for more information from your Case Manager and here in the *Courier* as this project continues. I think it will benefit all of us, help us to learn more and make needed changes.

Have a wonderful Spring. I'll be looking for you at our conference on May 20.

Cheryl Vines

## Calendar of Upcoming Events

The Oasis Renewal Center Support Group for People with Disabilities meets the third Tuesday of each month (April 26th). Supper is at 6:00 p.m. (with donations accepted to help defray the cost) followed by a program of music and a speaker/film or discussion. Call 225-6890 for reservations. Some transportation is provided

The Governor's Commission on People with Disabilites will meet April 21 at 10:00 am at St. James United Methodist Church on Pleasant Valley Rd.

The Arkansas Spinal Cord Injury Association meets the first Tuesday of every other month at Baptist Rehabilitation Institute in meeting rooms 2 & 3 at 6:30 pm. Contact Adrian Horton for more information at 568-6406.

To have activities announced in the upcoming issues of *Spinal Courier*, call the Editor at 324-9620 by 6/24/94 for the July issue or by 10/3/94 for the October issue.

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## SPINAL COURIER

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